Homecare support to improve adherence in multiple sclerosis

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Abstract

There are approximately 100 000 people in the UK who have been diagnosed with multiple sclerosis (MS). Long-term adherence by patients to the widely used treatment disease modifying therapies (DMTs) can be a challenge. The aim of this survey was to understand the critical points of contact where homecare support could impact adherence and provide suggestions to improve the homecare support services provided to MS patients. Homecare support is defined as any sponsored patient support programme from a homecare company. Surveys were sent to 5025 MS patients and 150 MS nurses working within the NHS. Completed survey responses were obtained from 1868 MS patients (37%) and 42 MS nurses (28%). Patients and specialist nurses reported that training and support in the early stages of treatment could influence adherence, particularly when that training is tailored specifically to the patients' requirements and unlimited by time and resources.

Key Words Multiple sclerosis, patient satisfaction, adherence, homecare services, patient training, evaluation

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Accepted 8 April 2011

This article has been subject to double-blind peer review

Multiple sclerosis (MS) is a long-term progressive disease. Research by the MS Society in 2009 demonstrated that there are approximately 100 000 people diagnosed with MS in the UK (Thomas et al, 2009). MS results from complex interactions between genetic and environmental factors. Genetic factors such as being a first, second or third degree relative of an MS sufferer increases the risk of developing the disease. Environmental factors indicate that MS is a disease of temperate climates and the prevalence increases with the distance from the equator. People with MS experience many different symptoms including fatigue, cognitive dysfunction, bowel and bladder dysfunction, weakness, spasticity, sexual dysfunction and visual problems.

There is currently no cure for MS and existing pharmaceutical treatments aim to slow the disease progression, prevent relapses and control patients' symptoms. These disease-modifying therapies (DMTs) have been available since the early 1990s. However, long-term adherence to DMT remains a challenge and will be discussed later. The National Institute of Health and Clinical Excellence (NICE) (2009) define adherence as: 'the extent to which the patient's action matches the agreed recommendations.

Steinberg et al (2010) found that those who adhered to their DMTs had better outcomes, including a lower risk of relapses, inpatient admissions and accident and emergency visits than those who did not adhere to their therapy. Furthermore, it was demonstrated that people with MS with a lower level of adherence with DMTs used unnecessary and potentially avoidable health-care resources. They concluded that it is important to explore ways to implement patient adherence programmes for people with MS on DMTs and that these programmes, at a minimum, should include patient education at the time of the first prescription and ongoing education and monitoring to assist patients in overcoming any potential barriers to adherence.

Costello et al (2008) reported adherence in the first 2–5 years of DMT to be 60–76%. However, Devonshire (2011) reported discontinuation rates of 14–47% over the initial 2–8 years of treatment, and indicated that discontinuation of therapy was more likely to occur early after treatment initiation (within the first 6 months–2 years), with the first 6 months reported to be the most critical time.

There are multiple barriers to adherence with DMT including problems with injecting, perceived lack of efficacy, and adverse events (Costello et al, 2008). Treadaway et al (2009) found that the most common reasons for missing treatment included: forgetting to administer the medication, not feeling like taking the medication, tired of the injections, or skin reactions or pain at injection sites.

Devonshire (2011) indicated that there is a need to study the benefits of an individualized approach to improving treatment adherence that includes such components as patient education, realistic expectations about treatment efficacy, and improved communication between patients, family members, and the physician.

An MS speciality care management programme was associated with improved treatment adherence and persistence, reduced risk of MS-related hospitalization and a decrease in MS-related medical costs (excluding pharmacy) (Tan et al, 2010). The full benefit of treatment can only be achieved through adherence to therapy, which could be influenced by patient support services and programmes, particularly in the early stages of treatment. However, further work needs to be carried out to determine the impact of these services and programmes on patient adherence.

This survey was conducted to generate the current level of satisfaction, evaluation and feedback from MS

Table 1. Outline of support provided to patients from the homecare companies

	Bupa Home Healthcare Ltd	Healthcare at Home Ltd	Peach Associates Ltd. with Sense Nurse team
Drug delivery	✓	✓	✗
Optional nursing support (if requested by MS nurse)	1. *Conduct patient training visit within specified timeframe and with defined objectives 2. Reinforce training and discuss side effect management during a follow-up visit or phone call if visit not required		1. * 2. Unlimited visits and phone calls to provide patient support at the judgement of Sense Nurse

Table 2. Comparison of the topics covered in the surveys

	MS patients	MS nurses
Length of time on treatment	✓	n/a
Level of satisfaction with homecare drug delivery	✓	✓
Potential improvements for drug delivery	✓	✗
Rating critical points of contact where homecare can influence adherence	✗	✓
General rating of homecare services in key areas	✗	✓
Who does the training and why	✗	✓
General rating of training to use medication	✓	✓
Requirements for further training	✓	✓

Table 3. Survey response rate

	Number surveys sent	Number surveys returned	Response rate
MS patients	5025	1863	37%
MS nurses	150	42	28%

patients, receiving interferon-β-1a (Rebif, Merck Serono) and MS Nurses, who manage people with MS, on the key aspects of the provided homecare support. It was conducted independently by Loyalty Chain Ltd and sponsored by Merck Serono UK. The aim was to produce information and data that could be used to rate the critical points of contact where homecare support could impact patient adherence and so improve the homecare support provided to patients as well as patients' overall experience of DMTs.

Survey design

Separate surveys sent to:

- 5025 people with MS—the total population of Rebif patients who received medication via one of three homecare companies as outlined in *Table 1*.
- 150 MS specialist nurses whose population represented all the MS prescribing centres in the UK and included the key nurses within each centre.

The overall aim of the survey was to provide information to improve the homecare services provided to patients with MS. The questions were designed to explore the current level of satisfaction, evaluation and feedback in key areas of homecare support for patients and MS nurses. MS nurses were additionally asked to rank the critical points of contact that homecare were involved in where they believed homecare could potentially impact patient adherence. The topics covered in the surveys can be found in *Table 2*. Questions were designed so that comparisons could be made between responses from patients and nurses. Survey questions presented predefined choices on a 4-point scale, to avoid central tendency bias. Both surveys were piloted with MS nurses to ensure appropriate language and that the predefined choices covered all possible options.

No attempts were made to correlate specific patient demographics or disease parameters with the topics covered in the survey. The patients were not asked about their own adherence as it was outside the scope of the survey and in order to ensure anonymity, no geographical variations were explored.

The patient surveys were sent out by post in May 2009 to patients and nurses. Study participants were given the option to complete the survey on paper or electronically. No reminders or follow up were considered for the MS patients as the response rate was sufficient to provide a representative sample with 99% confidence levels and 2.5% margin of error. The response rate for the MS specialist nurses also provided a representative sample with 90% confidence levels.

Survey findings

Response rate

The response rate to the surveys can be seen in *Table 3*.

Length of time on treatment

The length of time on treatment of the 1863 patients on Rebif can be seen in *Table 4*.

No associations were found between the length of time on treatment and other topics covered in the survey.

Adherence to treatment influences

The response of MS nurses regarding which critical points of contact, if any, homecare could impact patient adherence is shown in *Figure 1*. Nurses were asked to rate factors influencing patient adherence, with a rating of '1' for the point of contact they thought had the greatest influence and '2' for the next greatest and so on. They were asked only to rate the points of contact they felt had an impact. The scores were weighted and the total number of points for each 'point of contact' is shown as a percentage (*Figure 1*).

The 4 most important points of contact where the MS nurses indicated that homecare support had the greatest influence on patient adherence to treatment were:

- General communication and ease of contact (21% of available points)
- Patient training (20% of available points)
- Provision of accurate advice to patients (18% of

available points)
- Ongoing deliveries and dealing with delivery issues (17% of available points).

Drug delivery to patients

Patients were asked what 'one thing they would change about their drug delivery' (*Figure 2*).

Drug delivery was received from either Bupa Home Healthcare Ltd or Healthcare at Home Ltd. There was no significant difference between the patient responses from the different companies, therefore, the results between these two providers have been combined in this analysis.

- 969 patients reported being happy with their current deliveries (52%)
- 373 would change to a smaller delivery time slot (20%)
- 317 would change to deliveries to the evenings (17%)

Only 17 respondents indicated that greater reliability would be the one thing they would change about their current delivery (1%).

Patient training

Training was received from either MS nurses working in the NHS, Bupa Home Healthcare nurses, Healthcare at Home nurses or Sense nurses.

Of the 42 MS nurses surveyed, 80% indicated that they conduct the patient training themselves, while 20% delegated to the nurses at Bupa Home Healthcare, Healthcare at Home or Sense. The reasons the MS nurses gave for making their choice about which group conducted the training were:

- 12% chose who did the training based on quality of the training
- 24% chose who did the training based on the time frame to conduct training
- 29% chose who did the training based on the ease of arrangement
- 35% chose who did the training based on 'other' reasons. These included:
  - Local protocol and service requirements
  - Conducting training as part of case load
  - Using training to build a relationship with patient.

The patients were asked to rate how adequate they found their training and the MS nurses were asked to rate how adequate the training was that patients received from Bupa Home Healthcare, Healthcare at Home, Sense and themselves (*Figure 3*). The patients rated the training by the homecare companies as more adequate than the MS nurse's rating of the patients training by the homecare companies. The most consistent view of the training from the patients and MS nurses was the training conducted by the MS nurses. The biggest discrepancy between the nurses and patients' view of training adequacy was for the Bupa Home Healthcare. The discrepancy between how the MS nurses rated the training and how the patients rated the same training from the homecare companies could be due to the MS nurses perception being influenced by patients who are more likely to inform them when the training has been inadequate than they are if the training has been adequate.

Table 4. The distribution of time patients had been on treatment with Rebif

Time on Treatment	Up to 12 months	13–24 months	2–5 years	6–9 years	10+ years	Couldn't remember
Number	394	308	533	365	77	186
%	21	16	29	20	4	10

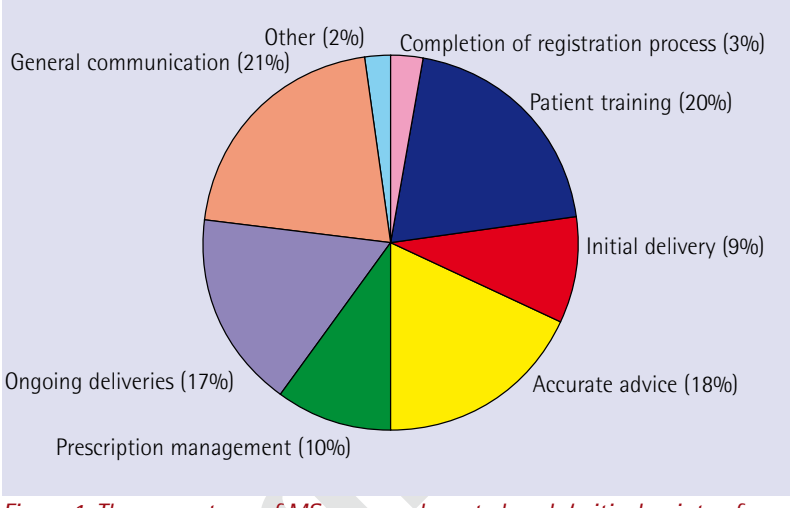

Figure 1. The percentage of MS nurses who rated each 'critical points of contact' in homecare support, as able to impact patient adherence.

Fifty percent of patients reported they were happy with the training that had been provided. In comparison, 9% of the MS nurses felt that no further training was needed for their patients when training was provided by another company. As outlined in *Table 5* both groups agreed that the three main areas that required further training was side-effect management, injection site rotation and how to inject.

General communication and ease of contact, and providing accurate advice to patients were rated in the top 4 areas where MS nurses indicated the homecare support had an influence. These two areas could potentially assist with some of the identified areas that benefit adherence; for example, ongoing patient education, setting realistic expectations about the treatment efficacy, helping to manage side effects and dealing with problems with injections.

Considerations from survey

This survey supported previous findings that homecare support services can have an impact on factors that are known to affect patient adherence to DMTs in MS (Tan et al, 2010). This survey indicates that MS nurses in the UK consider the critical points of contact for homecare with patients to be general communication, patient training, providing accurate advice to patients, ongoing deliveries and dealing with delivery issues. It has been suggested that patient education at the start

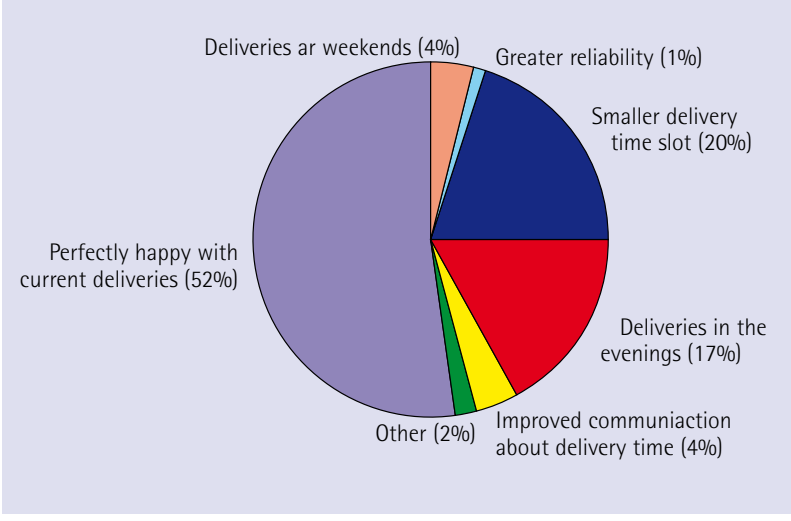

Figure 2. The percentage of each pre-defined aspect of drug delivery patients indicated as the one thing they would change about their current drug delivery system.

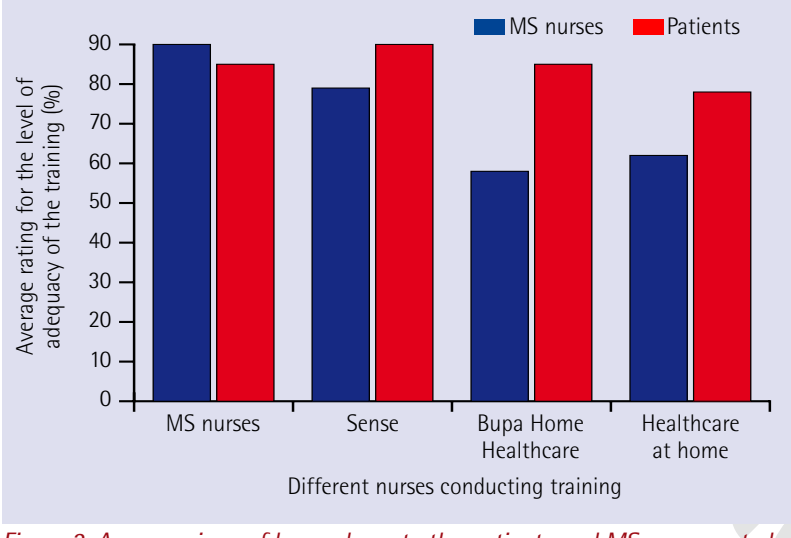

Figure 3. A comparison of how adequate the patients and MS nurses rated the patients training conducted by different nursing groups.

of treatment and ongoing education and monitoring is important for adherence to therapy—the first 6 months being critical (Steinberg et al, 2010; Devonshire, 2011). Therefore, patient training is an area where homecare may positively influence patient adherence to treatment. This is where the nurse trainer has the opportunity to teach the patient to inject, help manage potential side effects, reinforce advice and treatment expectations in line with the local MS centre and to set the standards for general communication.

Although the MS nurses felt that ongoing deliveries and dealing with delivery issues (17%) was an area that may impact patient adherence, 52% of patients were happy with their drug delivery and only 1% wanted greater reliability. The discrepancy in these results may be because some MS nurses have been responsible for resolving delivery issues between the patient and homecare company. This is one area where homecare delivery could improve communication with patients so MS nurses do not get involved and spend time on delivery issues.

Merck Serono contracts Bupa Home Healthcare and Healthcare at Home nurses to conduct training in one to two visits at the patients' home, and those nurses may have a portfolio of patients in other therapy areas. The contract with the Sense Nurses allows the number of visits and phone calls to be tailored to whatever they judge the patient needs. This results in some patients receiving many additional contacts (face-to-face visits and outbound phone calls) in the early stages of their treatment. As Sense nurses only work in the area of MS and endocrinology it allows them to specialize in the disease areas and fully understand the issues for patients. It is presumed that time and resources within MS centres make it difficult for MS nurses to provide such bespoke training to patients. The patients' response on how adequate they found their training did vary depending on who conducted the training. The training by Sense was considered the most adequate by the patients (90%) followed by MS Nurses (83%), Bupa Home Healthcare (82%) and Healthcare at Home (77%). Therefore, MS centres could use Sense nurses to augment their training when their time and resources are restricted or if a patient needs more intensive support.

The patients' response in the survey to the training from the Sense nurses demonstrates the benefits of the individualized training approach. What impact does a tailored approach have on patient adherence? *Figure 4* is data collated by Compufile Systems Ltd of Rebif patients over a 24 month period ending June 2009. At 24 months, 68% (n=2469) of the group supported by MS centres alone were continuing treatment compared with 82% (n=933) of the group support by both MS centres and the Sense team. These results were statistically significant (99% confidence level) indicating that homecare support services can increase persistence with Rebif in people with MS. However, homecare companies need to demonstrate their ability to provide high quality training and support that is easy to arrange within the MS nurses required time frame to MS centres.

Patients and nurses identified three areas where the patients training could improve:

- Side-effect management
- How to inject
- Injection site rotation

These are also areas that Tredaway (2009) included in some of the reasons why patients missed their injections along with forgetting and lack of motivation.

In order for homecare nurses to provide a more tailored support to MS patients, a greater understanding of why patients do not persist or adhere to treatment, outside of clinical reasons, needs to be established. This would involve further similar research constructing a patient treatment journey that would identify all the treatment milestones and understand the life events and changing attitudes to treatment that occurs

throughout the patients' treatment journey. This would help homecare nurses to provide individual support at the relevant time including motivating patients to continue with their treatment and providing ways to remind them to take their medication.

Limitations

- The patients included in this survey are all treated with Rebif and therefore care should be taken to extrapolate findings to patients on other DMTs
- The low response rate from the MS nurses (28%) and the patients (37%) may mean that the results aren't indicative of the whole MS nurse and patient population
- Geographical and demographical variations were not taken into account. They could have been potential confounding variables.

Conclusions

Homecare support services can have an impact on MS patients being treated with Rebif. Patients' initial training is a critical point of contact that may influence how a patient persists with his/her treatment. The adequacy of training can vary and the initial homecare support has greater impact when it is tailored to the patients needs and is unrestricted by time and resources. Homecare provides an additional resource for MS centres to help manage their MS patients and those that use the resource fully find that patients persist for longer on treatment. Therefore, homecare companies should work collaboratively with MS centres to improve the patient experience of treatment and possibly reduce the burden on NHS staff, especially in light of current and future financial constraints within the NHS and other health care systems.

However, there are areas that need further exploration: identifying reasons why patients do not or can not adhere to treatment, investigating geographical variations, quantifying the beneficial effects of patient support programmes and evolving technology in injection delivery devices on adherence rates. Constructing a patient's treatment journey to identify all the treatment milestones and understand the life events and changing attitudes to treatment may prove insightful. Appropriate homecare support, technology, education and motivational tools can then be designed to help patients at those key times. BJNN

Conflict of interest: *this study was supported by Merck Serono*

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Table 5. A comparison of areas for further training

Areas of further training	MS nurses	MS patients
Side effect management	28%	15%
Injection site rotation	21%	10%
How to inject	19%	14%
How to seek help	9%	5%
No further training required	9%	50%
Storage of medication	6%	2%
Ongoing deliveries	4%	1%
Understanding and usage of support material	4%	2%

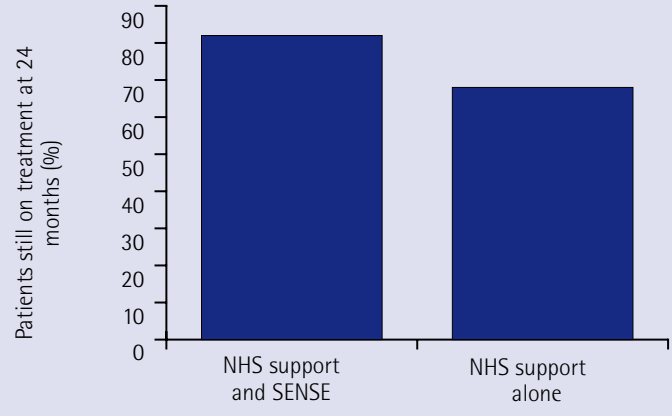

Figure 4. Comparison of the percentage of MS patients adhering to treatment after 24 months while supported either by a combination of MS centre and Sense or MS centre alone.

Key Points

- The benefits of treating MS with DMTs can only be achieved through adherence to medication. Patient support services and programmes, particularly in the early stages of treatment, can influence adherence.
- Homecare support services can have an impact on patient adherence particularly with patients' training, how they communicate to patients and by providing accurate advice and managing patient expectations.
- Patients' training is shown to improve persistence with treatment when it is tailored to the individual patients' requirements and is not restricted by time and resource.
- The combined tailored homecare training and MS centre support could be better utilized if NHS nurse specialists were more confident of the quality and ease of arranging the training within their required time frame.